A Qualitative Study on Educational Psychosocial Intervention to Learners with Sickle Cell Disease in Cameroon Schools.

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ABSTRACT

This study investigated the need for educational psychosocial intervention for learners with sickle cell disease. It further seeks to understand areas of psychosocial interventions and how education can support sickle cell patients psychologically and socially (psychosocially). The study was conducted at a sickle cell clinic using a descriptive case study design. A purposive sampling method was employed, and data were gathered through focus group discussions, each consisting of 12 participants, including learners and caregivers. Two separate groups participated in the study. The findings identified a significant need for psychosocial support among sickle cell patients and their caregivers.

From the findings, educational psychosocial intervention is an important aspect that schools need to implement to reduce the level of psychological problems such as stress, anxiety, depression, withdrawal, suicide though, and many others. In addition, sociological interventions could help build team spirit, integration of learners in schools, care, and love among learners, and create more awareness of SCD. The implementation of psychosocial support to learners with SCD in school is that such learners will be encouraged and it will create awareness and reduce the load bounden SCD has put on its victims. Thereby educational inclusion for sustainable development will become a reality UNESCO, (2014).

Keywords: sickle cell disease, patient, psychosocial and educational intervention. Educational support.

INTRODUCTION

According to Kengne et al. (2021), life is so unfair and full of pain, hopelessness, and terrible experiences for those suffering from sickle cell disease (SCD), a condition inherited at birth that is associated with severe morbidity. It also impairs the quality of life of those closely related to the patient (Khemani et al., 2019). Growing up and witnessing the suffering of sickle cell patients (SCP) is heartbreaking, as they frequently face numerous health challenges that affect their lives holistically. As a result, both family members and individuals endure significant challenges, including health-related, economic, psychological, sociological, and educational difficulties. Furthermore, providing psychosocial interventions to patients and learners with sickle cell disease while witnessing their struggles is a deeply painful experience to comprehend and express. This study will examine how institutions such as education can provide psychosocial support to learners with SCD. Numerous studies conducted on the burden of sickle cell disease like Zahran, et al. (2020), Mehe et al. (2020), and Adigwe et al. (2023) explain the degree of burden Sickle cell disease patient and their caregivers bears. Sickle cell disease is caused by an abnormality of the β-globin gene and is characterized by sickling of the red blood cells. Ngo et al. (2019) refer to it as a group of inherited red blood cell disorders with various acute and chronic complications including leg ulcers, priapism, fatigue, dizziness, osteonecrosis, bacteremia, ductility, renal disease, pulmonary hypertension, acute chest syndrome, and end-organ damage. Osunkwo et al. (2020). Hence, SCD is acknowledged to have a global impact by the World Health Organization (WHO), with traumatic public health implications. According to WHO (2020), sickle cell disease is a serious public health issue evaluated by Colombatti et al., (2019) who wrote that SCD is a disease that manifests in diverse

manners. Kengne et al., (2021) add that Sickle Cell Disease (SCD) is recognized as a public health problem due to its significant consequences. Research by Zahrane et al. (2020) and the World Health Organization (WHO, 2019) indicate that SCD imposes serious burdens, including psychosocial impacts, not only on individuals affected by the disease but also on their family members. External systems often neglect these individuals, which passively exacerbates their suffering, leading to increased psychological and social burdens.

Numerous studies have analyzed the psychosocial burden of SCD on individuals and their caregivers, including those by Wonkam et al. (2014) and Essien et al. (2023). This study aims to explore potential ways to alleviate these psychosocial burdens by examining how the educational system can contribute to the psychosocial well-being of learners affected by SCD through educational psychosocial interventions. By doing so, we hope to reduce their burden and improve educational outcomes for learners with sickle cell disease, while also raising awareness about SCD within both educational settings and the broader community.

LITERATURE REVIEW

In the current era, the world is advancing with the Sustainable Development Goals (SDGs), one of which is to implement inclusive education and education for all. Learners with Sickle Cell Disease (SCD) should not be overlooked, as noted by Bell et al. (2024). Inclusive education must address not only physical challenges and disabilities but also health challenges like SCD. There is a pressing need for policymakers and stakeholders to consider Educational Psychosocial Interventions (ESI) in schools and other institutions. Measures must be taken to enhance the social well-being of these individuals, emphasizing the responsibility of counsellors and institutions to provide educational psychosocial support through effective strategies for assisting students with SCD.

According to Mohanty (2020), the involvement of guidance counsellors in alleviating the psychosocial burden of learners with SCD is essential. This is achievable if policymakers and stakeholders establish and implement inclusive policies that consider the needs of patients with SCD. Implementing Educational Psychosocial Interventions in schools, particularly under the supervision of guidance counsellors, can yield positive results due to their critical role in providing psychosocial support to learners, including those affected by SCD and victims of gender-based violence. Furthermore, effectively implementing inclusive education aligns with the principles outlined in the Millennium Development Goals and Sustainable Development Goals (UN, 2000; UN, 2015).

Delgadinho (2022) and several other studies have highlighted the negative psychosocial experiences faced by patients with SCD. Additional research has examined the burdens on their caregivers and family members (Thomson et al., 2023; Arji et al., 2023; Bell et al., 2024). Despite the numerous challenges faced by learners with SCD, they must navigate their education like any other child, adhering to the same timetable and evaluations. In light of their health challenges and psychosocial burdens, Anie (2010) argues that appropriate psychosocial interventions for SCD patients are necessary within a global context.

Educational institutions should work to change cultural beliefs and attitudes, particularly regarding the stigma surrounding individuals with SCD. This includes providing interventions that create inclusive environments for learners at various educational levels and settings. According to Adigwe et al. (2023), approximately 80% of sickle cell disease cases occur in sub-Saharan Africa, where the sickle cell trait prevalence is estimated to affect between 10% and 40% of the population. In Cameroon, the estimated trait prevalence ranges from 20% to 30%, though this may be underreported due to data gaps in the region (Colombatti et al., 2023; Lancet, 2023).

Consistent educational psychosocial support is crucial in schools, clinics, and community-based settings, as emphasized by Adigwe et al. (2023). Okonji et al. (2020) suggest that psychosocial interventions can be delivered individually or through group counselling, utilizing a blended approach tailored to the individuals'

needs. Schools have a pivotal role in providing psychosocial intervention through guidance counsellors, who can implement therapeutic strategies that foster mindfulness, self-management, acceptance, and commitment to therapy. These efforts may help reduce health-related burdens, including the frequency of hospitalizations due to neglect, poor nutrition, and associated morbidity and mortality among SCD patients (Treanor et al., 2020).

Newman et al. (2020) elaborate on psychosocial theory, which emphasizes self-understanding, social relationships, and mental processes that connect individuals to their social world. Positive changes in these areas can be achieved by fostering better social relations among learners, both those with SCD and their peers. This approach can help mitigate internal factors such as depression, anxiety, and hopelessness, as well as external factors like stigma and rejection, which significantly impact the lives of learners with SCD in educational settings.

Pertinent Areas of Educational Psychosocial Intervention

The high morbidity and mortality rates among sickle cell patients (SCP) create an unending nightmare for victims and their families, leading to a state of fear, hopelessness, depression, low self-esteem, and anxiety (Lubeck et al., 2019). Additionally, Rakhi et al. (2018) highlighted how SCD reduces the life expectancy of those affected. Thomson et al. (2023) detailed the severity of sickle cell disease, noting that it is often accompanied by numerous other serious conditions, including acute and chronic complications, painful crises, and cumulative organ failure or damage. Not only does SCD result in high mortality, but it also contributes to poverty, which exacerbates psychosocial challenges such as rejection and stigmatization. These factors negatively impact learning, especially due to recurrent emergencies and hospitalizations among SCP. Some key areas necessary for educational psychosocial interventions for learners with SCD are illustrated in the diagram below.

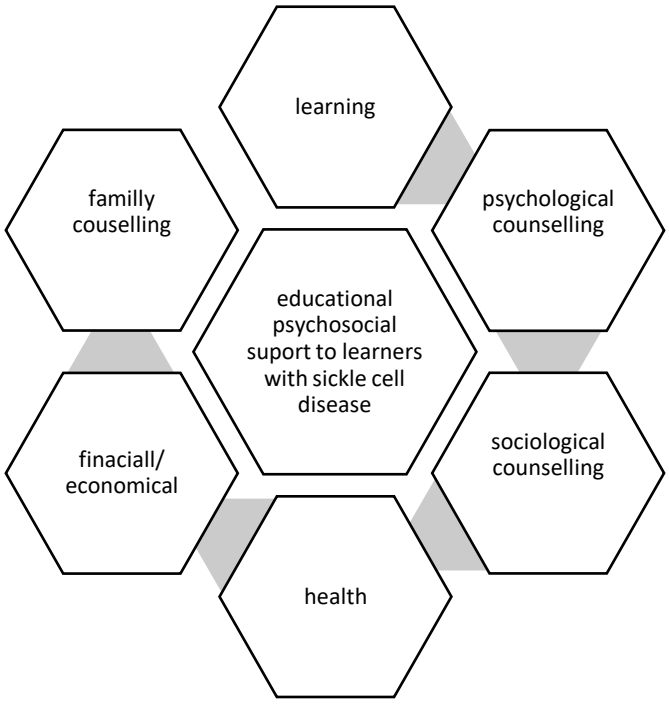

Fig. 1 Areas of Educational Psychosocial Intervention Learners to SCD

According to the renowned psychologist Albert Bandura, learning occurs through observation, imitation, and modelling. If school administrators, teachers, and guidance counsellors neglect learners with Sickle Cell Disease (SCD), other students may observe and replicate this attitude, thereby passively increasing the burden on those with SCD. Mel and Susie (2018) elaborated on the necessity for inclusive educational techniques to be contextualized, particularly within the African context, including considerations for SCD.

There is a critical need to tailor psychosocial interventions to engage with communities and collaborate to make education accessible for all. This serves as a roadmap for educational policymakers, stakeholders, and educational institutions to contextualize the principles of inclusive education and education for all by implementing psychosocial support for learners with SCD.

Psychologically

Managing a lifelong challenge can be particularly difficult, especially when surrounded by others who do not share the same experience. During counselling sessions with sickle cell patients (SCP) and their caregivers, they often express feelings of desperation, hopelessness, and the misery of their painful lives. Forsberg (2022) noted that prolonged exposure to psychological trauma impacts cognitive and emotional processes, particularly during childhood, and can negatively affect the neurodevelopment of the prefrontal cortex, thereby influencing IQ. Forsberg and Schultz (2023) further explained that these structures affect cognitive and emotional processes, as well as executive functions essential for learning, such as concentration, memory, attention, and thinking—cognitive processes that contribute to academic achievement. Psychosocial trauma can have severe, lifelong negative consequences (Lupien et al., 2018). Therefore, psychosocial intervention is critical.

Sociologically

Most studies have profoundly expressed that Sickle Cell Disease (SCD) affects the quality of life of its victims. Peil et al. (2023) and Munung et al. (2024) noted that many learners suffering from SCD face stigmatization both at home and within their educational environments. Much of African culture has perpetuated stigma against children with SCD, negatively impacting their emotions and leading to socio-emotional problems such as withdrawal and low self-esteem. These challenges make it difficult for learners with SCD to cope in their classrooms, school premises, and broader communities (Wonkam et al., 2014).

Health interventions

Sickle cell disease (SCD) is the most prevalent hereditary blood disease in humans with a high mortality rate, frequent and chronic diseases of different types. Saulsberry (2020), and Munung et al. (2024) explain that apart from hospital intervention there is a need for schools to have health facilities especially basic, or good accessibility to easy health interventions and for easy management of learners with SCD disease. Moreover, knowledge-based educational interventions for patients with SCD can improve self-management to reduce the frequency of sickness and hospitalization. Schools are encouraged to organise health talks that will give learners knowledge on how to manage and monitor their health. Also, the is a need for nutritional talk to help learners know what to eat to improve their wellness.

Economically/Financial support

Considering the psychological and social needs of learners with Sickle Cell Disease (SCD), assistance can be provided both indirectly and directly, as suggested by Troup (2021). In educational settings, indirect support can include the provision of school fees, learning materials, and links to organizations that offer assistance. These measures can significantly alleviate the financial and psychosocial burdens faced by families.

Family

The psychological impact of SCD on family members and caregivers is substantial, as noted by Wonkam et al. (2014). Additionally, Zahran (2020) highlighted the importance of education and family functioning in coping with SCD-related stress, anxiety, and depression, emphasizing that SCD hinders family growth both economically and otherwise. Therefore, stakeholders must be intentional in consistently encouraging patients and caregivers of SCD through the implementation of educational psychosocial support, and providing practical tips and awareness as advised by Rees et al. (2020). This support can be effectively delivered

through educational guidance counsellors, along with teachers and administrators, thereby contributing to the psychosocial well-being of these learners and reducing their burdens.

Psychosocial Support Interventions and Cognitive Therapy

Okonji et al. (2020) explain that psychosocial support interventions aim to improve well-being and reduce the burdens faced by victims, which can enhance adherence to learning and retention among adolescents. Tol et al. (2013) suggested that psychosocial well-being, achieved through individual and group counselling, fosters motivation, improves self-perception, and creates a sense of belonging. Psychoeducational interventions that reduce burdens through counselling and awareness are crucial. These educational interventions increase knowledge for better self-management and address challenges faced by learners with Sickle Cell Disease (SCD), their parents, and guardians. Treanor and Charlene (2020) emphasized that psychosocial psychoeducational interventions are important for alleviating the lifetime burdens on caregivers and individuals affected by SCD. Lubeck et al. (2019) noted that education is central to development and serves as a powerful tool for mental reformation and transformation, making it essential for educational systems to uphold interventions that contribute to learners' well-being and improve their academic performance (Shu, 2020).

Psychosocial Impacts of Sickle Cell Disease Unawareness

According to the Global, Regional, and National Prevalence and Mortality Burden for Sickle Cell Disease (2023), SCD is regarded as one of the most burdensome diseases worldwide. Ranque et al. (2021) estimated that the prevalence of sickle cell patients and carriers in Cameroon ranges from 30% to 40%, highlighting the urgent need to enhance education and awareness about SCD, particularly among young people. Sickle Cell Day, celebrated in June, often coincides with summer holidays in Cameroon, resulting in many parents and learners lacking a comprehensive understanding of SCD and its life-altering effects. Most studies on SCD focus primarily on genetics, typically within science classes, particularly biology, and often occur during critical examination periods, leading to increased student stress. Therefore, psychosocial and educational interventions are essential to raise awareness and reduce the societal burdens placed on individuals with SCD.

METHODOLOGY, SAMPLING, AND DATA COLLECTION

A qualitative approach was employed for this study, with data collected through interviews and focus group discussions targeting sickle cell patients and their caregivers. To ensure comprehensive information gathering, interviews were recorded. The study included 140 sickle cell patients and their caregivers, who meet every third Saturday of the month for medical follow-up. Permission was obtained from the attending physician for data collection. Focus groups consisted of 6 to 10 participants, with open-ended questions guiding the discussion, which lasted approximately 1 hour and 45 minutes.

This study reveals that, despite the pursuit of inclusive education, learners with SCD often find themselves neglected by the educational system. Research indicates that children with SCD frequently experience crises and miss classes each month (Agborndip et al., 2020). Attending a sickle cell clinic and receiving a secondary education were significantly associated with better knowledge of the condition.

Data Collection

This qualitative study primarily utilized the case series method, a descriptive approach for data collection. The case series method identifies several patients with similar experiences for the study (Chan & Mohhit, 2011). The researcher selected a center where a group of sickle cell patients meets regularly and obtained permission from their coordinator to conduct the study, as well as consent from the patients' parents or caregivers (Matthie et al., 2019). Purposive sampling was used to form focus group discussions (FGDs) for data collection. Based on participant willingness, a time was negotiated for in-depth interviews (IDIs).

Participants were notified in advance via their WhatsApp group and attended their monthly meeting. Study participants included individuals directly impacted by SCD, either as patients or family members, who had engaged in SCD education and schooling. Purposive sampling (Obilor, 2023) was used to select participants for the group interview.

By employing the case series method, data were collected through group in-depth discussions with individuals suffering from SCD. Participants included pupils or students from primary or secondary schools who meet every third Friday of the month for their clinic visit. The researcher, familiar with the group due to her voluntary counseling efforts, recorded the discussions. A total of 140 sickle cell patients and their caregivers were involved, with a sample size of 24 participants. Discussions were conducted on two occasions, each group comprising 12 members, and lasted approximately 1 hour and 45 minutes. The data obtained for this study are primary data.

Ethics Approval

Participants were reassured that information provided during interviews would be kept confidential, and participation was completely voluntary. The consent form was read and explain to them respondent was obtained from all participants

Table 1 Checklist of focused group

Inerview duration	**1 -2 hours**
Number of question	**6 base on the different factors**
Sample characteristic	**Learners from different schools**
Group size	**10**
Physical and observation	**Respondent were so sad and emotional**
instrument use in data collection	**Recording, by writing**
Environment	**Hospital environment**

FINDING AND DISCUSSION

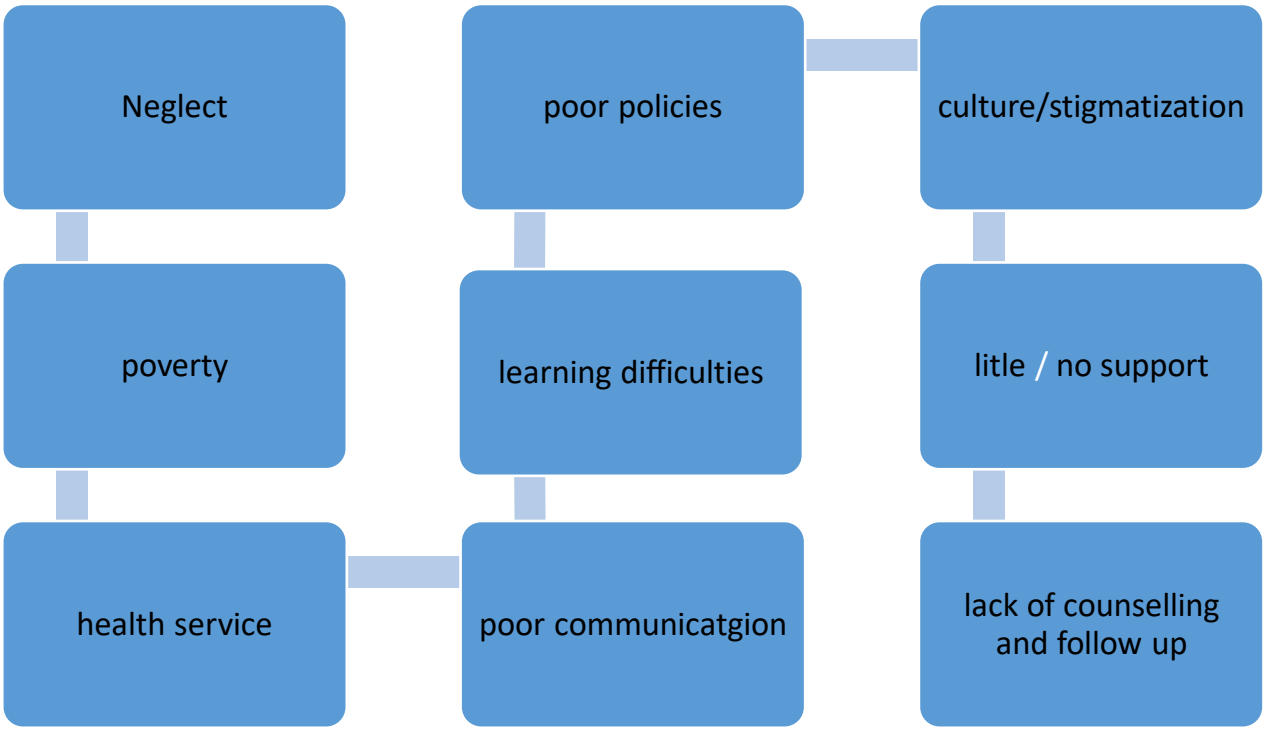

Fig 2 Shows the concern of the interviewer on the various aspect the need psychosocial support.

This section presents factual findings on the necessity of educational psychosocial support for learners with Sickle Cell Disease (SCD). The data were collected directly from patients rather than educational institutions, ensuring that the respondents' experiences are trustworthy and reflective of their realities.

According to the findings, learners with SCD in primary and secondary schools in Biyemassi, Yaoundé, reported dissatisfaction with how their conditions are managed within schools. Most respondents indicated they have never received educational psychosocial support. Emotionally, they expressed that, unlike their peers, they have not received any support in the areas highlighted in Figure 2. Respondents noted that they have observed internally displaced persons (IDPs), orphans, and others receiving social and emotional support, while they themselves have been overlooked. They also mentioned that patients with diseases such as HIV/AIDS receive attention even in hospitals, whereas they feel abandoned, with no support from government or international organizations. This neglect intensifies their feelings of rejection and abandonment, adding to their burdens.

Moreover, respondents reported that many find it challenging to study, not only due to their health but also because of frequent absenteeism. This creates gaps in their learning, making education difficult and often a nightmare due to their inability to keep up with classes. Their frustration is palpable as they feel nothing is being done to help them catch up academically, leading many to feel discouraged about continuing their education or sending their children to school.

Stigmatization, influenced by cultural factors, was another significant concern raised by respondents. This stigma manifests in the educational environment, where they experience increased rejection, resulting in isolation and making life unbearable, particularly within school premises. Furthermore, respondents emphasized the lack of awareness surrounding SCD; despite many suffering from the disease, both learners and parents often neglect to provide assistance during crises, opting instead to take patients to the nearest hospital or seek help from relatives. They pointed out that Sickle Cell Day, which is celebrated during summer holidays, limits awareness efforts, as fewer people are engaged during this time.

Fuller (2023) highlighted the need for national guidelines to assist individuals with SCD. The researcher proposes that the government should subsidize treatment for SCD patients to alleviate their burdens, as many families live in severe poverty due to frequent health challenges, making it difficult to cover hospital bills or maintain consistent medication access. This financial strain has led to the deaths of many children. Additionally, it is recommended that learning centers maintain basic health facilities at all times and employ physicians to improve the management of SCD in Cameroon.

Wonkam et al. (2013) conducted the first survey in Cameroon on the burden of SCD on parents of affected children, revealing that parents experience significant difficulties in coping with the situation. The government currently neglects this issue, as there are no policies addressing educational psychosocial interventions for learners with SCD. The researcher advocates for the government and other stakeholders to provide educational psychosocial support, establish follow-up systems, and implement health insurance schemes to support learners with SCD, particularly through a National Health Insurance Scheme covering school-aged children.

Brown et al. (2024) and Wonkam et al. (2013) emphasize the urgency of addressing SCD in sub-Saharan Africa. Increased attention within the educational system, in synergy with health and social welfare systems, is crucial to combat this endemic issue by creating awareness and enhancing knowledge about SCD.

SUGGESTION

1. Wonkam et al. (2014) state that frequent crises contribute to school absenteeism, while painful episodes and strokes lead to functional limitations and poor academic achievement or school dropout. This underscores the need for policies and practices that ensure psychosocial support for these individuals. Kato et al. (2018) noted that people with SCD experience varying levels of health, which

can significantly affect their psychosocial functioning. While some individuals cope relatively well, attending school and remaining active both physically and socially, others struggle to manage their conditions. Schools, through guidance counselors, must prioritize educational psychosocial support by providing counseling and educational follow-up for these learners. Additionally, with the growth of technology, schools can utilize educational technology (EdTech) for teaching purposes. The developmental trajectory of learners with SCD should not be expected to align with those of their peers who do not face similar health challenges.

2. The researcher proposes that the government take more serious actions regarding legislation related to SCD. Establishing awareness committees in schools, municipal councils, and religious organizations would educate communities and provide support to learners with SCD.
3. Furthermore, respondents indicated that the level of stigmatization they face is unbearable and greatly adds to their burden. This trauma makes them feel less human, leading to difficulties in coping within such environments. As a result, they often isolate themselves, even in the presence of others, which can lead to loneliness, anxiety, depression, and other psychosocial burdens.
4. Additionally, there is a critical need to holistically address other life aspects, such as education and nutrition, by connecting learners to health services, especially concerning the unpredictable nature of crises, including anemia, blood transfusions, viral infections, strokes, chest complications, priapism, leg ulcerations, and chronic organ failure. These conditions bring about fear, anxiety, and thoughts of mortality for patients, indicating that caregivers require better knowledge to handle SCD effectively. Despite the educational system's alignment with the United Nations Vision 2035 for inclusive education, it has yet to create adequate means to accommodate or support learners with SCD educationally. This is primarily due to the inconsistency in school attendance caused by frequent health challenges.
5. Financial burdens, as indicated by Wonkam et al. (2014), are also significant, compounding the psychological and social challenges faced. Frequent healthcare expenditures leave families struggling, while schools and local/international organizations often overlook the needs of SCD patients in favor of other health challenges.
6. The burden on caregivers is reportedly double, as they must manage the emotional and physical strain of assisting patients while sacrificing their own activities. This holistic stress significantly impacts the caregiver's well-being. Smith et al. (2021) reported that psychosocial support within health institutions and organizations aimed at improving patient survival is minimal and often fails to provide effective interventions for patients and caregivers.
7. Families and victims of SCD suffer from stigmatization, influenced by cultural factors and ignorance. This leads to isolation and depression among patients. The perceptions and reactions of those around them directly affect their psychosocial well-being and societal integration, making life increasingly difficult. Anie et al. (2010) highlighted that psychosocial problems pose major challenges for sickle cell patients, particularly during their school years, causing them to feel isolated from their peers and reluctant to engage in social activities. This isolation contributes to feelings of inferiority, anxiety, self-hatred, hopelessness, and depression, significantly hindering personal growth (Ngo et al., 2019).

CONCLUSIONS

The researcher concludes that school counselors must take psychosocial interventions seriously for the benefit of learners facing psychological and social challenges, particularly those with SCD. Implementing psychosocial interventions for this population is feasible and can be evaluated in real-life settings. Schools can collaborate with the government and humanitarian organizations to address these challenges. As scientific research continues to seek solutions for SCD, appropriate coping strategies and support mechanisms are essential to mitigate the psychosocial challenges faced by these individuals. Variations in study designs and consistency warrant caution in interpreting findings, and there is a notable lack of interventional studies in areas such as neuropsychology.

Moreover, while the goal of inclusive education is pursued, learners with SCD often find themselves

neglected by the educational system. Studies indicate that children with SCD frequently experience crises, missing an average of seven days of school each month (Agborndip et al., 2020).

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